

**CLIENT ASSISTANCE PROJECT**

**LEGAL ADVOCACY FOR PERSONS  
WITH DEVELOPMENTAL DISABILITIES**

**MENTAL HEALTH LAW PROJECT**

**PROTECTION AND ADVOCACY FOR  
INDIVIDUAL RIGHTS**

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**TO: Interested Persons**

**FROM: Anne L. Henry**

**RE: Options for Family, Guardian Reimbursement for Services Provided to Persons  
with Disabilities**

**DATE: March 31, 2000, Updated October 4, 2000**

Because of the significant workforce shortage and a growing desire to make individual choices about services, there is a lot of interest in payment of family members and guardians for services provided to persons with disabilities. The issues in this area are somewhat convoluted and have been creating confusion as to whether Minnesota is using options available in other states or not. The following information is provided to clarify which opportunities Minnesota has or is in the process of developing:

**1. Consumer Support Grant (CSG).**

**A. State-Funded Consumer Support Grant.**

The current Consumer Support Grant program allows families to use the state share of Medical Assistance funded home care services in a flexible and individualized manner. The problems with the current CSG program include:

- 1) The amount of money available is less than half the amount paid by Medical Assistance for home care and waiver services. The statute allows persons to use the state share of Medical Assistance (48.5% in 2000), but also allows a 20% deduction for administrative costs by the state and county. DHS has stated that any county which asks for the full 48.5% of Medical Assistance state share is given authority to use the full 48.5% without any deductions for administrative costs. There are currently no restrictions on use of state CSG funds to reimburse parents of minors or adults or spouses for services provided.

- 2) Participation in the CSG program is a county option. Only 12 of 87 counties actually have persons participating in the CSG program. As of August 2000, 84 individuals or families were using the CSG program in those 12 counties.

**B. Consumer-Directed Home Care (CDHC) Federal Demonstration Waiver (Section 1115).**

Legislation adopted during the 1999 session requires the Commissioner of Human Services to apply for federal permission to add federal funds to the state funds already available in the current Consumer Support Grant program. The Department of Human Services has decided to use the Federal 1115 Section Demonstration Waiver process. Minnesota's 1115 Demonstration Project waiver request, entitled "Consumer Directed Home Care," was submitted in May 2000 to the federal Health Care Financing Administration (HCFA). DHS hopes to have federal approval for this Demonstration Project by the summer of 2001.

DHS is pursuing the CDHC 1115 Demonstration Project as a Home Care Services Project to include Personal Care, Home Health Aide and Private Duty Nursing Services, but not including waived services. If HCFA approves Minnesota's 1115 Demonstration Project request to add federal money to the state Consumer Support Grant program, this would offer the option of flexible use of service dollars under a plan developed at the county level. It is likely, if approved, that the service dollars would be placed in a joint account with the county or other fiscal agent rather than direct cash payments to families. There are federal restrictions on the payment of parents of minors and spouses with federal Medicaid funds.

2. Personal Care Assistant Program.

A. Payment Of Family Members.

Federal Medicaid regulations prohibit payment of a member of an individual's family acting as a PCA.. Federal regulations further define "family member" as a legally responsible relative. This means that under federal law, Minnesota cannot reimburse the parent of a minor or a spouse for provision of PCA services. However, any other family member, including siblings, aunts, uncles, stepparents and grandparents can be paid. Parents of adults (18 or over) who are not the legal guardian can clearly be reimbursed for PCA services. Parents of adult recipients who are the legal guardians can be reimbursed for providing PCA services beginning July 1, 2000 due to a change in state law which is only effective for one year. It is important to note that unless the

adult PCA recipient can direct his or her own care, Minnesota requires that a responsible party, other than the PCA, reside with the PCA recipient. The DHS Bulletin describing legal guardian PCA relative hardship waiver is #00-56-19, July 27, 2000, available through the DHS website, [www.dhs.state.mn.us/infocenter/doc.htm#bull](http://www.dhs.state.mn.us/infocenter/doc.htm#bull).

Minnesota's PCA statute allows the following relatives to provide PCA services under a hardship waiver: 1) Parents, whether or not they are the guardian of adult recipients (18 years or older); 2) Adult children of recipients; and 3) Siblings who are at least 16 years old. Other relatives such as stepparents, grandparents, aunts or uncles, can be paid as a PCA without a hardship waiver. Again, it is important to remember that our state law requires that recipients who cannot direct their own care must have a responsible party, who cannot be a paid PCA, living with them in order to receive PCA services.

**B. PCA Choice Option (called "Fiscal Agent Option" in state law).**

1. Changes made by the 1999 Legislature require DHS to offer a **"fiscal agent option"** for PCA recipients. DHS expected to have this fiscal agent option in place by July 1, 2000, but the Bulletin needed for implementation was delayed. The Bulletin describing the "PCA Choice Option" should be issued during October of 2000 and will be available on the DHS website [www.dhs.state.mn.us/infocenter/docs.htm#bull](http://www.dhs.state.mn.us/infocenter/docs.htm#bull). Federal approval for this change has been obtained.
2. The PCA Choice Option will allow a recipient or responsible party to:
  - a. hire and terminate the PCA,
  - b. recruit and hire professional supervision (RN or mental health professional),
  - c. supervise and evaluate the PCA in areas that do not require professional supervision, and
  - d. flexibly use funds currently used by provider organizations for administrative functions,
  - e. contract with a fiscal agent to pay the PCA and all state and federal tax, FICA and other obligations.

f. The PCA Choice Option should allow recipients or their families to modestly increase PCA pay, but will not change the rules about which family members can be paid as PCA's.

3. In October 1999, the Health Care Financing Administration (HCFA) made revisions to requirements for the PCA program. These new revisions clarify that a person who cannot direct their own care could still participate in Minnesota's PCA Choice Option (called Consumer Directed Services at the federal level) if another family member oversees the services. Minnesota already has in place a surrogate for those who cannot direct their own care, termed "the responsible party" in our state PCA law. These recent HCFA revisions offer no change in the prohibition against paying spouses and parents of minors.

3. **Home and Community Waiver for Persons with Mental Retardation or a Related Condition (MR/RC Waiver).**

A. **Residential Habilitation Option Under The MR/RC Waiver.**

DHS issued a bulletin (98-56-15) dated October 21, 1998, which announced changes in Minnesota's MR/RC waiver plan regarding immediate family members providing residential habilitation services. Family members, with the exception of parents/stepparents of minor children and spouses of adult recipients, who meet provider qualifications may provide residential habilitation services. In other words, family members, such as parents of adult children, may be employed by an agency and provide residential habilitation services. Parents who are legal guardians of adults should be able to work for a waived services provider and be paid for residential services. DHS has received federal approval for this change, but the Bulletin announcing the change has not been issued as of October 2000.

B. **Consumer-Directed Community Supports Under The MR/RC Waiver.**

Minnesota received approval from HCFA at the end of 1997 to add Consumer-Directed Community Supports to the MR/RC waiver. The service option termed "Consumer Directed Community Supports" is offered in counties (only 11 as of October 2000) which enter into a memorandum of understanding (MOU) with the state regarding protections and quality assurance for persons using Consumer-Directed Community Supports. This option allows services to be individually designed, using either formal or informal providers. At this time, spouses and parents

of minor children cannot be reimbursed for any services provided through Consumer-Directed Community Supports.

Minnesota now has federal approval to allow reimbursement of legal guardians of adults who are employed by an agency or are reimbursed through a Consumer-Directed Supports plan. The state Bulletin implementing this change is expected by late fall, 2000.

The Consumer-Directed Community Supports service option is only available through the MR/RC waiver. DHS has committed to extending the Consumer-Directed Community Supports service option to the other waiver programs for nursing home level of care (CADI), hospital level of care (CAC) and traumatic brain injury nursing home or neurobehavioral hospital level of care (TBI) by January 2001.

Minnesota's Consumer-Directed Community Supports is much like a similar option in Wisconsin's home and community waiver. Wisconsin patterned their request after Minnesota's and received approval for this option about six months after Minnesota's federal approval.

4. Federal Issues Regarding Reimbursement For Parents Of Minors And Spouses For Services.

Federal Medicaid has had a long-standing rule against allowing spouses or parents of minor children to be reimbursed for services which "would normally be provided without charge as a matter of course in the usual relationships among members of a nuclear family." This position has been interpreted by the federal government to mean that exceptions could be made for "extraordinary services requiring specialized skills such as skilled nursing or physical therapy." Parents and spouses who are nurses or therapists (but not PCAs) could be reimbursed according to federal law. Under Minnesota law, spouses can be reimbursed for caring for a disabled spouse under the hospital level of care waiver (CAC), but a parent of a minor child who is a nurse, cannot be reimbursed.

Given the severe workforce shortage and the fact that some family members are foregoing other employment or limiting their activities in order to care for their child, federal policy should be changed to allow payment to parents of minors and spouses who act as PCAs. It appears that West Virginia may have gotten just such a policy change for parents of minors when an extreme hardship due to lack of a qualified provider under the home and community waiver exists. However, West Virginia's option would not apply to the PC A program which has specific federal regulations prohibiting parents of minors from being reimbursed for services. Until federal law changes, DHS ought to pursue the option of allowing parents of

minors to provide services under the home and community waiver and Section 1115 Demonstration Waivers with safeguards and monitoring.

Efforts are underway to pass federal changes to allow parents of minors to be reimbursed. One bill in Congress which may be amended to deal with this issue is the Grassley, Kennedy Family Opportunity Act, which has not been amended or passed as of October 2000.

## **SUMMARY.**

### **I. CURRENT LAW ALLOWS THE FOLLOWING OPTIONS:**

#### **A. All Family Members.**

**All family members**, including the parent of a minor, legal guardian or a spouse can be reimbursed through the Consumer Support Grant program with state funds only (limited to a maximum of 48.5 percent of M.A. home care expenditures), provided: 1) the county participates in the program; 2) the county approves a plan for such reimbursement. **NOTE: This program is a county option. The county board and county social service agency administrators are the key decision makers.**

#### **B. Parents Of Minors, Spouses, And Other Family Members.**

1. Parents of minors cannot be reimbursed for services through any Medical Assistance funded program, including home and community waivers, PCA, private duty nursing.
2. Spouses can only be reimbursed for private duty nursing in limited circumstances under the hospital level of care (CAC) waiver.
3. **Family members, except parents of minors and spouses**, can be reimbursed for services through the 1) the Residential Habilitation Option as staff of a provider agency under the MR/RC waiver or 2) for PCA services. Hardship waivers are necessary for parents of adult recipients, adult children of recipients and siblings who are paid as PCA's. Other relatives such as stepparents, aunts, uncles, nieces, nephews, step-siblings, or grandparents do not need a hardship waiver to be paid as a PCA.

**C. Legal Guardians For Adults.**

1. DHS has amended the MR/RC waiver plan to allow legal guardians for adults to be reimbursed under the MR/RC home and community waiver, including for Consumer-Directed Community Supports services.
2. Legislation allowing legal guardians for adults to be paid as PCA's became effective July 1, 2000 for only one year. (The Legislature could extend the effective date of this provision during the 2001 Session). For PCA recipients who cannot direct their own care, an adult residing in the household who is **not** paid as a PCA must act as the responsible party. *See #2, pages 2-3.*

**II. CHANGES MINNESOTA COULD MAKE TO EXPAND REIMBURSEMENT FOR FAMILY MEMBERS.**

- A. Federal law allows the reimbursement of parents of minor children who are nurses, therapists or providers of other specialized services. Minnesota could change current policy to allow reimbursement for these "specialized services" by parents to their minor children.
- B. The policy on spouses could be expanded to include reimbursement for "specialized services" beyond the currently allowed nursing services and current limit of 24 hours per week.
- C. DHS could request home and community waiver amendments to allow parents of minors and spouses to be reimbursed for habilitative, personal support or independent living services based upon the work force crisis. The federal response from HCFA on this type of request is unknown, but given the crisis, our state should make the request.

**III. FEDERAL CHANGES NEEDED.**

- A. Federal regulations prohibiting payment of parent of minors or spouses as PCA's should be changed to allow reimbursement. Provisions regarding hardship, labor market, and health and safety protections should be considered in developing the parameters of this change.
- B. Federal HCFA policy limiting parents of minors and spouses to being paid for providing "extraordinary services requiring specialized skills" should be broadened to

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include services provided when staff for authorized services are unavailable. Again provisions setting forth conditions and protections should be included.

ALH:pjc/nb